

RELATIONSHIPS BETWEEN INFORMATION ADEQUACY, ILLNESS PERCEPTIONS,
AND DISTRESS AMONG SURVIVORS OF DIFFERENTIATED THYROID CANCER

by

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ABSTRACT

Patients and survivors of differentiated thyroid cancer (DTC) report experiencing significant distress despite excellent disease prognosis. Predictors of distress in this population, however, are largely unexplored. Two factors that relate to distress in other cancer populations are patient subjective experiences with information provision and patient illness perceptions. Thus, evaluation of information experiences and illness perceptions among survivors of DTC is warranted. In particular, the unique prognosis and treatment associated with DTC invites investigation of the relationship between patient subjective experiences with information quantity (termed “information adequacy” in this study) and distress in this population. Thus, the primary goals of this thesis are 1) to examine how information adequacy and illness perceptions relate to distress in survivors of DTC, and 2) to investigate illness perceptions as a mechanism by which information adequacy and distress are related. Further, research suggests that distress and reduced emotional functioning among survivors of thyroid cancer extend years after initial diagnosis; however, the relationship between time and distress among survivors of DTC remains unclear and understudied. The extent to which time moderates relationships between information adequacy, illness perceptions, and distress also remains unexplored. Thus, secondary goals of this thesis are 1) to examine the relationship between time (specifically “years-since-diagnosis”) and distress, and 2) to examine time as a moderator of relationships between information adequacy, illness perceptions, and distress in survivors of DTC.

A sample of 284 participants identified in the Patient Reported Outcomes Following Initial Treatment and Long-term Evaluation of Survivorship (PROFILES) registry were included in structural equation modeling. Relationships between information adequacy, illness

perceptions, and distress were evaluated in Model 1. Results largely supported the hypothesized model: greater information adequacy was associated with better illness perceptions, better illness perceptions were associated with less distress, and greater information adequacy was indirectly related to less distress via better illness perceptions. A direct relationship between information adequacy and distress, however, was not observed. Secondary thesis aims were explored in Model 2. Results did not support moderation hypotheses, and a direct relationship between years-since-diagnosis and distress was not demonstrated. A revised model yielded ancillary findings that having fewer years-since-diagnosis was associated with worse illness perceptions, and with greater distress via worse illness perceptions. Thus, overall study results revealed a notable relationship between illness perceptions and distress among survivors of DTC. Future research should investigate whether interventions to address illness perceptions result in decreased distress in this population. The demonstrated link between information adequacy and illness perceptions invites further investigation of informational interventions in particular as a method to address illness perceptions. Future research should also investigate the extent to which illness perceptions mediate relationships between information experiences and distress in other cancer populations.

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INTRODUCTION AND LITERATURE REVIEW

The Thyroid Gland: A Brief Overview for Clinical Health Psychologists

The thyroid gland, located in the front of the neck, serves an essential role in regulating cell metabolism (Yen & Brent, 2013). The thyroid gland operates through secretion of thyroid hormones: particularly, L-triiodothyronine (T3) and L-tetraiodothyronine (T4; Yen & Brent, 2013). These hormones impact metabolic rate through mechanisms that relate to the use and release of energy, including mitochondrial oxidative phosphorylation and Na⁺/K⁺-ATPase (the sodium-potassium pump), among other processes (Yen & Brent, 2013). Thyroid hormones are regulated through a negative-feedback loop within the Hypothalamic-Pituitary-Thyroid (HPT) axis (Salvatore, Davies, Schlumberger, Haly, & Larsen, 2011). Hyperthyroidism (overactive thyroid hormone production) and hypothyroidism (underactive thyroid hormone production) reflect imbalances in these hormone levels (Brent & Davies, 2011; Mandel, Larsen, & Davies, 2011). Such imbalances affect metabolic processes, and may cause changes in weight, cardiac health, and mood, among other symptoms (Brent & Davies, 2011; Mandel et al., 2011). Given the importance of healthy thyroid functioning in maintaining the body's regulatory functions, thyroid conditions must be managed effectively by medical professionals. For some conditions, such as thyroid cancer, treatment itself may result in hormone imbalance that must be subsequently managed (Pacini et al., 2006). The long-term management of hormone levels among patients with thyroid cancer reflects the importance of regulating thyroid hormone activity, even in the absence of the body's natural production of these hormones. Thyroid hormone regulation for thyroid cancer patients in particular will be elaborated in subsequent sections of this thesis.

Thyroid Cancer: An Introduction

Thyroid cancer diagnoses represent a small percentage of all cancer diagnoses reported yearly (Schneider & Brenner, 2013). It was estimated that in 2015, 62,450 new cases of thyroid cancer were diagnosed, representing approximately 3.8 percent of new cancer cases diagnosed in the United States in 2015 (National Cancer Institute, 2015). Rates of diagnosis, however, are increasing rapidly: between 1992 and 2012, thyroid cancer diagnoses increased by approximately five percent per year in the United States (Howlader et al., 2015). These increases in rates of diagnosis have also been observed outside of the United States, including in many European countries (e.g., Colonna et al., 2007; Gomez et al., 2004; Rego-Iraeta, Pérez-Méndez, Mantinan, & Garcia-Mayor, 2009; Smailyte, Miseikyte-Kaubriene, & Kurtinaitis, 2006).

Thyroid carcinomas may be classified into several primary subtypes, distinguished by the cells that the carcinomas derive from, and other disease characteristics. Papillary and follicular carcinomas represent the majority of thyroid cancer diagnoses, with papillary thyroid carcinomas comprising approximately 84 percent of thyroid carcinomas, and follicular carcinomas representing approximately 10 percent of diagnosed thyroid carcinomas (Aschebrook-Kilfoy, Ward, Sabra, & Devesa, 2011). Papillary and follicular thyroid cancers are collectively referred to as “differentiated thyroid cancers” (DTC), and such carcinomas originate from thyroid follicular cells (Fagin & Nikiforov, 2013). By contrast, medullary thyroid carcinomas involve calcitonin-producing cells of the thyroid gland, and represent approximately two percent of thyroid carcinomas diagnosed each year (Aschebrook-Kilfoy et al., 2011; Hu, Jimenez, Cote, & Gagel, 2013). Anaplastic, or undifferentiated thyroid carcinomas are the most rare and aggressive thyroid carcinomas, consisting of less than two percent of diagnosed thyroid carcinomas (Aschebrook-Kilfoy et al., 2011; Klopper, Kane, & Haugen, 2013). The remaining

thyroid cancer diagnoses, representing less than two percent of those diagnosed, are “other” or unspecified thyroid carcinomas (Ashebrook-Kilfoy et al., 2011). Ten-year survival rates for patients with thyroid cancer are over 90 percent (Howlader et al., 2015). Prognoses are particularly favorable for patients with DTC: estimates of 10-year survival rates for thyroid cancer patients are approximately 93 percent for papillary thyroid cancer and 85 percent for follicular thyroid cancer (Hundahl, Fleming, Fremgen, & Menck, 1998). By contrast, 10-year survival rates are approximately 75 percent for medullary thyroid cancer, and 14 percent for anaplastic thyroid cancer (Hundahl et al., 1998).

Operative treatment to remove the carcinoma is almost always indicated in treatment of DTC (Randolph & Doherty, 2013). For patients with DTC, surgery is often followed by radioactive iodine therapy (RIT; Filetti, Tuttle, & Sherman, 2013). RIT is primarily used to destroy residual thyroid tissue, and to monitor patients for any disease recurrence. Use of radioactive iodine post-operatively is referred to as radioiodine remnant ablation (RRA). RRA is used to destroy thyroid tissue leftover from surgery. It is primarily employed to destroy any residual carcinoma and leftover healthy thyroid tissue. Destruction of residual malignant cells is essential for treatment, for the purpose of preventing disease recurrence. Furthermore, destruction of residual healthy thyroid tissue is often indicated, because presence of such tissue may mask detection of disease recurrence. Disease recurrence is often detected by the presence of specific markers emitted by malignant cells. Healthy thyroid tissue, however, emits these same markers. Thus, destruction of the healthy thyroid tissue ensures that the presence of such markers is indeed indicative of disease recurrence (Filetti et al., 2013). Given the cost and side effects associated with RIT, however, use of ultra sound in lieu of RIT is becoming more common for the purpose of monitoring disease recurrence (Filetti et al., 2013).

Thyroid hormone replacement therapy post-surgery is routine for long-term treatment of many thyroid cancer survivors (Filetti et al., 2013). The median age of diagnosis for patients with thyroid cancer is 50 (National Cancer Institute, 2015). Thus, long-term treatment may last many decades. Though thyroid hormone replacement therapy may not be indicated for all patients, especially those demonstrating a low-risk of disease recurrence, it remains an essential part of treatment for many thyroid cancer survivors (Biondi, Filetti, & Schlumberger, 2005). Hormone replacement therapy is typically administered at TSH-suppressive doses, because TSH levels following removal of a thyroid carcinoma is associated with disease recurrence (Filetti et al., 2013). Thus, properly administered hormone therapy prevents hypothyroidism resulting from reduced thyroid hormone levels, and also aids in preventing disease recurrence by maintaining TSH levels in a low range (Pacini et al., 2006). Thus, while the majority of thyroid cancer patients retain a favorable prognosis in terms of mortality, continued treatment is often essential to remain cancer-free.

Thyroid Cancer and Distress

Distress levels for thyroid cancer patients appear to be greater than in various comparison groups, as indicated by greater endorsement of anxiety, and in some studies, depression. DTC patients, for example, have reported greater levels of anxiety on the Hospital Anxiety and Depression Scale (HADS) compared with the general German population (Tagay et al., 2006; Tagay et al., 2005). These findings have been replicated with other comparison groups. In a study by Hoftijzer and colleagues for example, 153 DTC patients reported higher levels of anxiety on the HADS compared with age- gender-, and socioeconomic status-matched healthy control individuals (Hoftijzer et al., 2008). In the same study, Hoftijzer and colleagues found that DTC survivors reported greater levels of depression on the HADS compared with the two

age-, gender-, and socioeconomic status-matched healthy groups (Hoftijzer et al., 2008). Such results suggest that thyroid cancer patients experience greater anxiety and depression compared with healthy individuals.

Several studies have additionally demonstrated that thyroid cancer patients report reduced emotional functioning relative to comparison groups. Husson et al. (2013a), for example, found that compared with an age and sex-matched population, thyroid cancer survivors reported lower scores on the emotional functioning scale of the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30). Additionally, compared with the general German population, DTC patients reported lower scores on the emotional role limitations subscale and on the mental component summary of the health survey short-form 36 (SF-36; Tagay et al., 2005). Results of these studies highlight the emotional impairment experienced by thyroid cancer survivors. Of additional concern, studies have demonstrated that impairments in quality of life extend beyond emotional functioning: compared with age and sex-matched controls, thyroid cancer patients have reported greater fatigue, and lower social, physical, role, and cognitive functioning (Hoftijzer et al., 2008; Husson et al., 2013a; Tagay et al., 2005).

Evidence suggests that distress and reduced emotional functioning among patients with a history of thyroid cancer extend many years beyond diagnosis. In the study conducted by Hoftijzer and colleagues, for example, elevated symptoms of anxiety and depression were found for a cohort of 153 cancer survivors with a mean of 6.34 years since cure (Hoftijzer et al., 2008). In a related study of 150 DTC patients, impairments in emotional role functioning and vitality were observed for individuals who had been diagnosed, on average, 5.5 years prior to data collection (Crevenna et al., 2003). Evidence regarding the extent to which distress and

emotional functioning improve over time, however, is mixed (Crevenna et al., 2003; Hoftijzer et al., 2008; Husson et al. 2013a). Such results highlight the importance of addressing thyroid cancer patients' long-term emotional needs, and invite further examination of the extent to which time (e.g., time since diagnosis) is related to distress in this population.

Information Experiences and Distress in Cancer

Relationships between subjective information experiences and distress in cancer populations have been evaluated in numerous research studies. A review paper by Husson and colleagues concluded that, in general, perceptions of having received greater quantities of information, greater satisfaction with information, and greater clarity of information are associated with decreased distress in cancer patients and survivors (Husson et al., 2011b). One prospective study found that among 135 breast cancer patients, perceived exposure to a greater amount of information shortly after diagnosis predicted lower depression scores on the HADS three-six months later. Further, perceived exposure to a greater quantity of information was associated with higher scores on the global quality of life scale of the EORTC QLQ-30 (Vogel, Leonhart, & Helmes, 2009). In a related prospective study of 82 head and neck cancer patients, satisfaction with information before treatment predicted fewer endorsed depressive symptoms on the HADS 6-8 months after treatment (Llewellyn, McGurk, & Weinman, 2006). The study revealed that decreased satisfaction with treatment also predicted lower scores on the mental health component summary score of the SF-12.

Similar to prospective studies, cross-sectional studies have demonstrated significant relationships between information experiences and distress. In one study of 1040 cancer survivors, higher unmet information needs were associated with lower scores on the mental component summary of the SF-36. Specifically, survivors who reported desiring additional

information in a greater number of specified categories (e.g., tests and treatments, side effects and symptoms) were more likely to score lower than the study average on the mental component summary score (Beckjord et al., 2008). In a related study of 231 breast cancer patients, satisfaction with information was associated with decreased distress, as measured by the Impact of Events Scale (Griggs et al., 2007). The study additionally found a direct relationship between satisfaction with information and better reports of mental health and vitality, as measured by the SF-36. A related study of endometrial cancer, lymphoma, multiple myeloma and colorectal cancer patients found increased satisfaction with and perceived helpfulness of information to be associated decreased anxiety and depression on the HADS (Beekers, Husson, Mols, van Eengeren, & van de Poll, 2015). Furthermore, a study of 214 patients diagnosed with either breast or prostate cancer demonstrated significant relationships between information satisfaction and emotional well-being, as measured by the Functional Assessment of Cancer Therapy (FACT-G; Davies, Kinman, Thomas, & Bailey, 2008). The latter study found that increased information satisfaction was also associated with better-reported global quality of life.

Thus, research suggests that patient subjective experience with information provision may prove an important target in preventing and reducing distress in cancer patients. Few research studies, however, have been conducted for patients with a history of thyroid cancer in particular. One study conducted by Husson and colleagues found “unmet information needs” to be associated with high impact of cancer in thyroid cancer patients (Husson et al., 2014). While such results suggest that thyroid cancer patients’ information needs are related to the experienced effects of cancer, the effect of information provision on distress specifically has not been addressed. Further, thyroid cancer patients cite a lack of informational support to be one of the most difficult aspects of managing their disease, and report that receiving more information

about the disease would improve their satisfaction with care (Banach et al., 2013). Thus, exploring relationships between distress and information experiences, and in particular between distress and patient perceptions regarding quantity of information provided is relevant in addressing self-reported needs of thyroid cancer patients. Further, given that treatment of DTC is often long-term due to hormone replacement therapy, investigation regarding the extent to which time and information experiences interplay to affect distress levels is warranted.

Illness Perceptions and the Common-Sense Model

Illness perceptions refer to the cognitive and emotional representations that patients generate about their illnesses. Cognitive representations in particular are often associated with the “common-sense model” of illness perceptions (Leventhal et al., 1997; Leventhal, Brisette, & Leventhal, 2003). This model posits relationships between health-related stimuli, cognitive representations of stimuli, and subsequent health-related action. Two premises underlie the common-sense model: people act as “common sense scientists” when constructing cognitive representations of illness threats, and patients generate goals for illness self-management based upon these cognitive representations (Leventhal et al., 2003, p.49).

The common-sense model arose from the parallel process model of illness (Leventhal, 1970). The parallel process model posits that emotional states of fear and distress arise in response to health threats, and cognitive representations of the threat are developed (Leventhal et al., 2003). Corresponding procedures (action plans) for managing both the distressing emotions and threats are then conceptualized. Patients subsequently enact action plans for the purpose of reducing the fear and danger experienced from the perceived health threat (Leventhal et al., 2003). Thus, the cognitive representations that arise from the perceived threat serve an important role in influencing patient health behavior.

The common-sense model expands upon the parallel processing model by further explaining the nature of cognitive representations within this process. The common-sense model was developed in light of a series of related studies that illustrated cognitive representations as arising in five key areas: “identity”, “cause”, “timeline”, “consequences”, and “cure” (Leventhal et al., 1997; Leventhal et al., 2003). Briefly stated, “identity” refers to the symptoms and labels associated with the illness. “Cause” refers to the perceived causes of the illness. “Timeline” refers to the expected duration or age of onset of the illness. “Consequences” refers to the impact on functioning and severity of pain. “Cure,” or “controllability” refers to the perceived preventability, curability, and controllability of the illness (Leventhal et al., 2003).

Representations of illness may change in response to a variety of sources, including patient experience and input from interpersonal relationships such as friends and doctors (Leventhal et al., 2003). Factors impacting patient illness perceptions are important to understand, because of the theoretical role of illness perceptions in guiding health-related behaviors. Furthermore, numerous studies have demonstrated that worse illness perceptions are associated with, and often predict, worse health outcomes. Specifically illness perceptions are associated with distress, disability, coping strategies, psychological well-being, social functioning, and vitality (Hagger & Orbell, 2003; Petrie & Weinman, 2012). In some studies, illness perceptions have predicted health outcomes regardless of baseline disease severity (e.g., Juergens, Seekatz, Moosdorf, Petrie, & Rief, 2010). Thus, exploring non-clinical factors related to patient representation of illness may facilitate understanding of how to improve health outcomes.

Illness Perceptions: Recent Developments in Theory

Recent research on illness perceptions has extended Leventhal's theory through study of additional cognitive and emotional representation domains. Specifically, these additional domains include "illness coherence" and "emotional representations." Illness coherence, a cognitive domain, evaluates the extent to which patients endorse understanding their illness. Illness coherence has been studied alongside the original cognitive domains for the purpose of evaluating "meta-cognition" in the way a patient evaluates the "coherence or usefulness of his or her illness representation" (Moss-Morris et al., 2002, p.2). Illness coherence has proven to independently predict illness outcomes (e.g., Traeger et al., 2009). Additionally, the study of the emotional representation domain has facilitated examination of patients' emotional representations of illness that, according to theory, arise in parallel to cognitive representations in response to health threats (Leventhal et al., 2003; Moss-Morris et al., 2002). Evaluation of emotional representations has also facilitated understanding of patient response to illness (e.g., Rozema, Völlink, & Lechner, 2009; Scharloo et al., 2005).

Further extension of the common-sense model of illness includes the division of the control representation into two separate but related domains: "treatment control" and "personal control." The division reflected results from previous illness perceptions studies in which patients' patterns of control perceptions suggested the presence of two distinct domains (Moss-Morris et al., 2002). Additionally, Leventhal's timeline representation has been evaluated as two separate domains: "timeline (acute/chronic)" and "timeline cyclical." Again, such a division addressed results from illness perceptions studies that suggested the presence of separate domains (Moss-Morris et al., 2002).

One criticism associated with the common-sense model is related to measurement of the theory. The primary measure utilized to measure illness perceptions is the Illness Perception Questionnaire-Revised (IPQ-R; Moss-Morris et al., 2002). The IPQ-R consists of eight subscales, with one subscale representing each of the domains described above (identity, timeline acute/chronic, timeline cyclical, consequences, treatment control, personal control, illness coherence, emotional representations), and an additional section evaluating causes. Some researchers have suggested that modifications to the IPQ-R would enhance psychometric properties (e.g., Ashley et al., 2013; Nicholls, Hill, & Foster, 2013). Psychometric evaluation of illness perception measures is undoubtedly an important area of further research, with important implications for illness perception theory. Regardless, the IPQ-R continues to be the primary measure utilized to measure illness perceptions, and has led to important discoveries regarding patient outcomes. Research findings related to illness perception feelings are elaborated below.

Illness Perceptions and Distress

Research studies utilizing measures of illness perceptions have illuminated relationships between illness perceptions, distress, and other health outcomes. Juergens and colleagues, for example, found illness perceptions before cardiac surgery to predict later depressive symptoms. (Juergens et al., 2010). Specifically, overall worse illness perceptions, as measured by the IPQ-R, predicted higher depression scores on the HADS. Furthermore, more threatening perceptions were associated with higher scores on the Pain Disability Index and lower scores on the physical functioning scale of the SF-12. Baseline illness severity did not mediate the relationships between illness perceptions and distress, disability, or physical functioning. Such results suggest that illness perceptions do not simply reflect illness severity, and may be independent predictors of health outcomes. In a related study, a cross-sectional survey of 74 patients with low-grade

brain tumors (diagnosed approximately 27.26 months prior to the study) revealed that worse illness perceptions on the IPQ-R predicted higher levels of anxiety and depression on the HADS (Keeling, Bambrough, & Simpson, 2013). Specifically, causal perceptions predicted anxiety, and both causal and identity perceptions predicted depression. Additionally, in a study of 214 men with prostate cancer, lower scores on the illness coherence and treatment control subscales of the IPQ-R were associated with lower scores on the emotional well-being scale of the Functional Assessment of Cancer Therapy (FACT; Traeger et al., 2009). In the same study, attribution of illness to internal causes was associated with worse emotional well-being.

For newly diagnosed patients with head and neck cancer, illness perceptions have predicted emotional functioning, in addition to physical, role, cognitive, and social functioning. Scharloo and colleagues, for example, found that patients who reported more disease-specific symptoms, a greater likelihood of illness recurrence, greater attribution of illness to personal actions, and stronger emotional reactions to illness reported lower quality of life scores on the QLQ-30 (Scharloo et al., 2005). In a related study of illness perceptions among breast cancer patients, emotional representations and lower perceived treatment control perceptions were associated with worse scores on the mental health scale of the RAND-36 quality of life measure (Rozema et al., 2009). Furthermore, one study of illness perceptions among 334 patients diagnosed with either breast, colorectal or prostate cancer found illness perceptions to predict quality of life 15 months after diagnosis (Ashley, Marti, Jones, Velikova, & Wright, 2015).

Clearly, illness perceptions are related to patient distress. Few studies, however, have been conducted with thyroid cancer patients exclusively. One study found that illness perceptions were unrelated to cancer stage in patients with a history of DTC; however, the study found that negative perceptions were related to fewer years since last treatment, and to a greater

number of iodine treatments (Hirsch et al., 2009). Prior research has not examined the relationship between DTC patients' illness perceptions and distress specifically. Thus, examination of this relationship among patients with a history of DTC is needed. Further, given the long-term medical follow-up associated with DTC and evidence of a relationship between time since last treatment and illness perceptions, investigation regarding the extent to which time affects the relationship between illness perceptions and distress is warranted

Illness Perceptions and Information Experiences

It is clear that patient information experiences and patient illness perceptions are related to distress in patients with chronic illness. The common-sense model of illness posits that acquiring information about one's illness is a mechanism by which illness perceptions can change. Therefore, one might expect research studies to demonstrate empirical relationships between information experiences and illness perceptions. The relationship between information experiences and illness perceptions was explored in one study of 3080 cancer survivors with previous diagnoses of lymphoma, multiple myeloma, endometrial, or colorectal cancer (Husson et al., 2013b). Specifically, subjective information experiences regarding quantity of information received were examined in relation to illness perceptions. Results revealed that perceptions regarding quantity of disease-specific information, and satisfaction with quantity of information received were associated with better illness perceptions, as measured by the Brief Illness Perceptions Questionnaire (B-IPQ): a greater quantity of perceived received disease-specific information was associated with a greater sense of personal and treatment control, in addition to a greater reported illness understanding. By contrast, information about other services (e.g., different places of care, aspects of managing illness at home) was associated with beliefs of negative consequences, longer illness duration, less treatment control, more experienced

symptoms, less understanding, and stronger emotional reaction to their illness. Additionally, increased satisfaction with quantity of information received was associated with better illness perceptions in most domains.

Despite statistical support for the theoretical impact of information acquisition on illness perceptions, illness perceptions have not been explored as mechanism by which information experiences affect distress. Examination of these relationships among DTC survivors may provide needed information regarding distress in this population, while introducing a model by which distress in other chronic illness populations may be examined. Further, given the notably favorable prognosis and unique course of treatment associated with the disease, patient subjective experiences with quantity of information received (hereafter referred to as “information adequacy”) are of particular interest to examine alongside illness perceptions and distress. If such relationships are demonstrated, further investigation regarding the extent to which these relationships are affected by time may contribute to a greater understanding regarding the effects of time, information adequacy, and illness perceptions on distress in this population.

PRESENT STUDY

The primary goals of this study are: (1) to examine how information adequacy and illness perceptions relate to distress in survivors of DTC and (2) to investigate illness perceptions as a mechanism by which information adequacy and distress are related. It is hypothesized that greater information adequacy will be associated with less distress. It is also hypothesized that illness perceptions will mediate the observed relationship between information adequacy and distress. Specifically, it is hypothesized that greater information adequacy will be associated with better illness perceptions, better illness perceptions will be associated with less distress, and a significant indirect relationship of information adequacy and distress will be demonstrated via illness perceptions. Secondary goals of this thesis include (1) to examine the relationship between time (specifically “years-since-diagnosis”) and distress, and (2) to examine time as a moderator of relationships between information adequacy, illness perceptions, and distress. It is hypothesized that fewer years since diagnosis will be associated with greater distress, and will moderate demonstrated relationships between information adequacy, illness perceptions, and distress.

Method

Participants

Participant data for this study was obtained from a population-based survey completed by thyroid cancer survivors in the Patient Reported Outcomes Following Initial Treatment and Long-term Evaluation of Survivorship (PROFILES) registry (van de Poll-Franse et al., 2011). The PROFILES registry utilizes data from the Netherlands Cancer registry (formerly Eindhoven Cancer Registry) to facilitate research on longitudinal psychosocial and physical outcomes for

cancer patients. The Netherlands Cancer Registry collects clinical data for all patients recently diagnosed with cancer in the southern part of the Netherlands (Janssen-Heinen, Louwman, Van de Poll-Franse, & Coerbergh, 2005). All patients diagnosed with thyroid cancer between 1990 and 2008, as registered in the Netherlands Cancer Registry, were eligible to complete the population-based survey from which the present study derives its data ($N = 568$). Patients were excluded if significant cognitive impairment or other physical illness ($N = 31$) or unverifiable addresses ($N = 90$) precluded participation. Further, one hospital declined participation ($N = 86$), and six patients died prior to study commencement. The survey was mailed to the remaining 355 patients, 334 of which had a history of DTC specifically (Husson et al., 2014; Husson & Horevoorts, 2012). The survey consisted of demographic and clinical questions, in addition to a number of established psychosocial measures (Husson & Horevoorts, 2012). Results from the survey were entered into a dataset, then de-identified and made available to outside researchers. The present study utilized a subset of demographic, clinical, and psychosocial information available from the aforementioned dataset.

Measures

Demographic and Clinical Variables. Demographic and clinical information included gender, age at time of questionnaire, age at diagnosis, years since diagnosis, tumor type, primary treatment, disease stage, partnership, education level, and employment.

Information Adequacy. Information adequacy variables were derived from a Dutch translation of the EORTC QLQ-INFO25 (INFO25; Arraras et al., 2010). The INFO25 is a 25-item self-report measure consisting of questions regarding information patients received throughout the course of disease and treatment. The measure consists of four subscales regarding perceptions of quantity of information received in the following domains: disease,

medical tests, treatment, and other services. The measure also contains eight single items. Answer choices for individual scale items are presented on a four-point Likert scale, except for four of the single items that are presented in binary scale. The present study utilized scores from the four information-quantity subscales and from single item “Were you satisfied with the amount of information you received?” Scale scores are linearly converted to a 0-100 scale, with higher scores on items utilized for this study reflecting greater information adequacy (i.e., perceptions of having received a greater quantity of information, and greater satisfaction with quantity of information). Internal consistency and test-retest reliability for all scale scores are established: Chronbach’s alpha $\geq .70$ and intraclass correlation values (ICC) $>.71$ for all scales (Arraras et al., 2010).

Illness Perceptions. Illness perceptions in the present study were measured using a modified version of the Brief Illness Perceptions Questionnaire (B-IPQ; Broadbent, Petrie, Main, & Weinman, 2006). The B-IPQ is a nine-item self-report questionnaire measuring patients’ cognitive and emotional representations of illness. The measure was developed as a brief alternative to the widely used 50-item IPQ-R. Responses for the first eight items of the B-IPQ are presented on a 0-10 Likert-scale. Summary scores are computed by reverse-scoring items 3,4, and 6, and then summing responses to the first eight items of the measure (Broadbent, n.d.). Higher summary scores indicate overall more threatening or worse views of illness. The ninth item, an open-ended question regarding causal perceptions, is evaluated qualitatively (Broadbent, n.d., Broadbent et al., 2006). The present study utilized a Dutch translation of the measure, with response items presented on a 1-10 Likert scale. The B-IPQ summary score was used to evaluate the role of illness perceptions within the context of the proposed statistical models.

Psychometric properties of the Dutch translation of the B-IPQ (first eight items) have been

established in previous research: Chronbach's alpha = .73, and Intraclass Correlation Coefficient = .72 (Hallegraeff, van der Schans, Krijnen, & de Greef, 2013).

Distress. Distress was measured utilizing a Dutch translation of the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The HADS is a 14-item measure, consisting of two seven-item subscales: anxiety and depression. Items are scored on a four-point Likert-scale. Higher scores on items indicate greater symptomatology. Subscales are computed by summing the responses for the individual items consisting of the scale. Internal consistency for the anxiety and depression scales is established: in a sample of 3080 cancer survivors, Chronbach's alpha was .83 and .78 for anxiety and depression, respectively (Beekers et al., 2015).

Statistical Methods

Structural equation modeling was selected as the primary analytic plan to test study hypotheses. While aspects of information adequacy have been evaluated in numerous research studies, to our knowledge information adequacy has not been examined as a latent variable in structural equation modeling. Thus, a CFA was conducted to evaluate the statistical viability of an information adequacy latent variable. The measured information variables discussed previously (the four subscale scores of the INFO25, and the single-item satisfaction question from the INFO25) were included in the CFA. These variables included "disease", "medical tests", "treatment", "other services", and "satisfaction."

Then, a series structural equation models was conducted to test hypotheses of mediation and moderation. Two latent variables, information adequacy and distress, were included in analysis. Results of the CFA (see Results) informed indicators of the information adequacy variable. Indicators of this latent variable included "disease," "medical tests," "treatment," and

“satisfaction.” The distress latent variable was associated with two indicators: the HADS subscale scores (“anxiety” and “depression”). One illness perceptions measured variable was included: the summary score of the B-IPQ (“illness perceptions”). The moderation model included the same variables as the mediation model, in addition to the moderator variable “years-since-diagnosis”: a continuous measured variable representing the number of years since diagnosis of DTC. Data was prepared in SPSS Version 23, and subsequent analyses (i.e., CFA and SEM) were conducted in Mplus.

Results

Participant Characteristics

Participants in this study included 334 patients diagnosed with DTC between 1990 and 2008 in the southern region of the Netherlands. Respondents consisted of 285 patients who mailed back the survey; Non-respondents consisted of 49 patients who did not return the survey. One patient was excluded from analysis because of risk of traceability¹. Demographic and clinical characteristics of Respondents and Non-respondents are displayed in Table 1. Partnership, education, and employment information was not available for Non-respondents. There were no significant differences between Respondents and Non-respondents on any other demographic or clinical variables. Non-respondents were not included in any further analyses.

¹ Note: Participant was removed to protect confidentiality

Table 1 *Participant Demographic and Clinical Characteristics*

| | Respondents (<i>n</i> = 284) | Non-Respondents (<i>n</i> = 49) |
|---|---|--|
| Gender | | |
| Male | 67 (23.6%) | 14 (28.6%) |
| Female | 217 (76.4%) | 35 (71.4%) |
| Age at time of questionnaire (<i>M, SD</i>) | 55.98 (14.12) | 54.31 (9.76) |
| Age at diagnosis (<i>M, SD</i>) | 46.31 (14.51) | 44.55 (16.77) |
| Years since diagnosis (<i>M, SD</i>) | 9.67 (5.36) | 9.76 (5.25) |
| Tumor Type | | |
| Papillary | 216 (76.1%) | 37 (75.5%) |
| Follicular | 68 (23.9%) | 12 (24.5%) |
| Stage at Diagnosis | | |
| I | 168 (59.2%) | 29 (59.2%) |
| II | 51 (18.0%) | 22 (22.4%) |
| III | 43 (15.1%) | 6 (12.2%) |
| IV | 17 (6%) | 3 (6.1%) |
| Unknown | 5 (1.8%) | 0 (0%) |
| Primary Treatment | | |
| Surgery alone | 67 (23.6%) | 10 (20.4%) |
| Surgery + ablation | 207 (72.9%) | 39 (79.6%) |
| Surgery + radiotherapy | 8 (2.8%) | 0 (0%) |
| Other | 2 (.7%) | 0 (0%) |
| Partnership | | |
| Partner | 224 | - |
| No Partner | 60 | - |
| Education Level* | | |
| High | 76 | - |
| Middle | 177 | - |
| Low | 30 | - |
| Employment* | | |
| Employed | 147 | - |
| Not Employed | 132 | - |

*Note. Numbers do not count to 284 because of missing values.

Descriptive Statistics of Model Variables

Prior to structural modeling, descriptive statistics were performed on all variables to be included in models. Non-normality was observed among several variables (observed skewness and kurtosis values significantly different than 0 at .01 alpha level; Tabachnick & Fidell, 2013). As transformations resulted in data that remained skewed, a model estimator (MLR) robust to assumptions of normality was selected for subsequent analyses (performed on untransformed data). Specifically, MLR utilizes robust standard errors with corresponding adjusted fit indices to address non-normality in model estimation (Muthén & Muthén, 2012). Further, MLR addresses missing data via utilization of maximum likelihood estimation, facilitating retention of participants with missing data (Muthén & Muthén, 2012). Descriptive statistics of model variables are displayed in Table 2.

Table 2 *Descriptive Statistics of Model Variables*

| | <i>M(SD)</i> | <i>Skew(SE_{skew})</i> | <i>Kurtosis(SE_{kurtosis})</i> |
|--|---------------|--------------------------------|--|
| Information Variables (0-100 scale) | | | |
| Disease | 50.64 (21.54) | .336 (.151) | -.253 (.301) |
| Medical Tests | 66.67 (24.13) | -.309 (.151) | -.460 (.300) |
| Treatment | 41.66 (21.41) | .481 (.151) | .138 (.302) |
| Other Services | 14.66 (20.40) | 1.86 (.153) | 3.74 (.305) |
| Satisfaction | 52.51 (28.00) | -.066 (.149) | -.566 (.298) |
| Illness Perceptions Variable (8-80 scale) | | | |
| Illness Perceptions | 34.36 (12.98) | .116 (.150) | -.259 (.300) |
| Distress Variables (0-21 scale) | | | |
| Anxiety | 4.63 (3.76) | 1.06 (.150) | 1.217 (.299) |
| Depression | 3.36 (3.13) | 1.15 (.149) | .874 (.298) |
| Clinical Variable (Range: 2.04-20.96 yrs.) | | | |
| Years-Since-Diagnosis | 9.67 (5.36) | .343 (.145) | -.976 (.288) |

Information Adequacy Latent Variable: Confirmatory Factor Analysis (CFA)

The initial CFA model for the information adequacy latent variable consisted of five indicators: “disease”, “medical tests”, “treatment”, “other services,” and “satisfaction.” Fit indices for the initial model indicated poor fit of the hypothesized model to the data based on common criteria (Hu & Bentler, 1999). Specifically, fit indices revealed Root Mean Square Error of Approximation (RMSEA) = 0.106, Comparative Fit Index (CFI) = 0.972, and $\chi^2(5) =$

20.325, $p = 0.001$. Further inspection of model results revealed a noticeable discrepancy between the amount of variance accounted for in the “other services” indicator by the model (23.6%) versus the amount of variance accounted for in the other indicators by the model (51.2%-75.0%). Further, conceptual considerations suggested the possibility that “other services” was related to a similar, but distinct construct from the other variables: whereas “disease,” “medical tests,” and “treatment” assessed information directly pertinent to primary course of medical care, “other services” assessed information beyond the scope of primary course of medical care (e.g., self-care and psychological support). Thus, the model was revised to exclude “other services.” Results from the revised model suggested that the hypothesized model fit the data well (RMSEA = 0.055; CFI = 0.996; $\chi^2(2) = 3.618, p > .05$), and all factor loadings were significant. The resulting information adequacy latent variable was included in subsequent SEM analysis.

Information Adequacy, Illness Perceptions, and Distress

Primary study hypotheses regarding relationships between information adequacy, illness perceptions, and distress were tested in a structural model. The initial hypothesized model is featured in Figure 1.

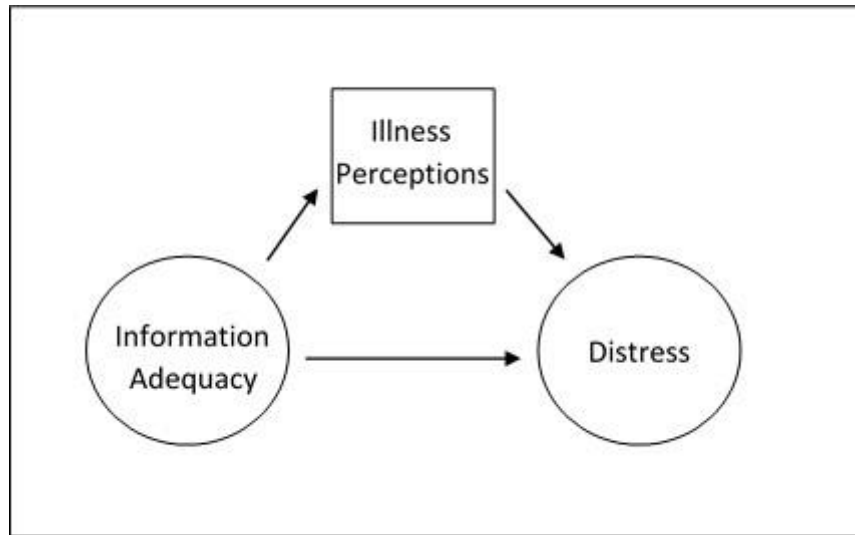


Figure 1 *Model 1.1: Conceptual model of hypothesized relationships between Information Adequacy, Illness Perceptions, and Distress*

Fit indices suggested that the hypothesized model fit the data well (RMSEA = 0.043; CFI = 0.991; $\chi^2(12) = 17.997, p > .05$). The paths from information adequacy to illness perceptions ($\beta = -0.132, SE = 0.063, p = 0.037$), and from illness perceptions to distress ($\beta = 0.530, SE = 0.052, p < 0.001$) were significant, indicating that greater information adequacy was associated with better illness perceptions, and better illness perceptions were associated with less distress. The direct pathway from information adequacy to distress was not significant ($\beta = -0.039, SE = 0.089, p = 0.664$), suggesting a lack of direct relationship between these two variables; however, the indirect pathway from information adequacy to distress through illness perceptions, was significant ($\beta = -0.070, SE = 0.035, p = 0.043$). This indirect relationship suggested that relationship between information adequacy and distress was dependent on the relationship of both of these variables to illness perceptions. Given the hypothesized importance of illness perceptions within the relationship between information adequacy and distress, and an absence of any research suggesting a strong direct relationship between these two variables among the

DTC population, the model was amended to exclude the direct relationship between information adequacy and distress (see Figure 2). Resulting indices revealed that the hypothesized model fit the data well (RMSEA = 0.035; CFI = 0.993; $\chi^2(13) = 17.395, p > .05$). All pathways were significant. Specifically, the direct pathways from information adequacy to illness perceptions ($\beta = -0.134, SE = 0.064, p = 0.035$), and from illness perceptions to distress ($\beta = 0.536, SE = 0.050, p < 0.001$) were significant, as was the indirect pathway from information adequacy to distress through illness perceptions ($\beta = -0.072, SE = 0.035, p = 0.042$). The model supported hypotheses: greater information adequacy was associated with better illness perceptions, better illness perceptions were associated with less distress, and greater information adequacy was related to less distress via illness perceptions. This model accounted for 28.7% of the variability in the distress latent variable.

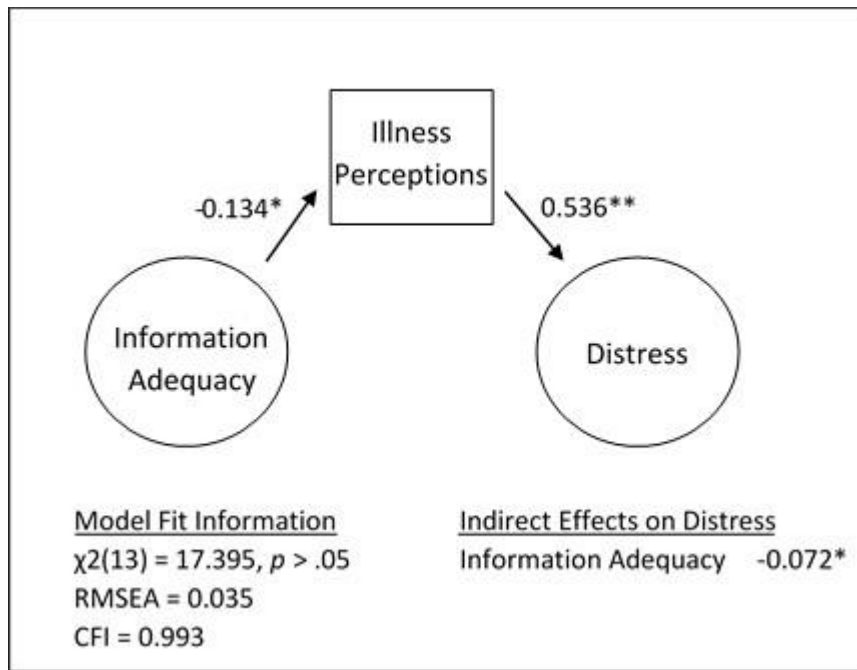


Figure 2 Model 1.2: Statistical model of relationships between Information Adequacy, Illness Perceptions, and Distress

* $p < .05$; ** $p < .01$

Effect of Years-Since-Diagnosis

Secondary study hypotheses regarding the relationship between years-since-diagnosis and distress, and regarding moderating effects of years-since-diagnosis were tested in Model 2.1 (see Figure 3). Interaction variables were created to test moderation hypotheses (i.e., whether years-since-diagnosis moderated the relationships observed in Model 1.2). Measured variables utilized in creation of interaction variables (i.e., “years-since-diagnosis” and “illness perceptions”) were mean-centered prior to creation of interaction terms for the purpose of addressing multicollinearity (Little et al., 2007).

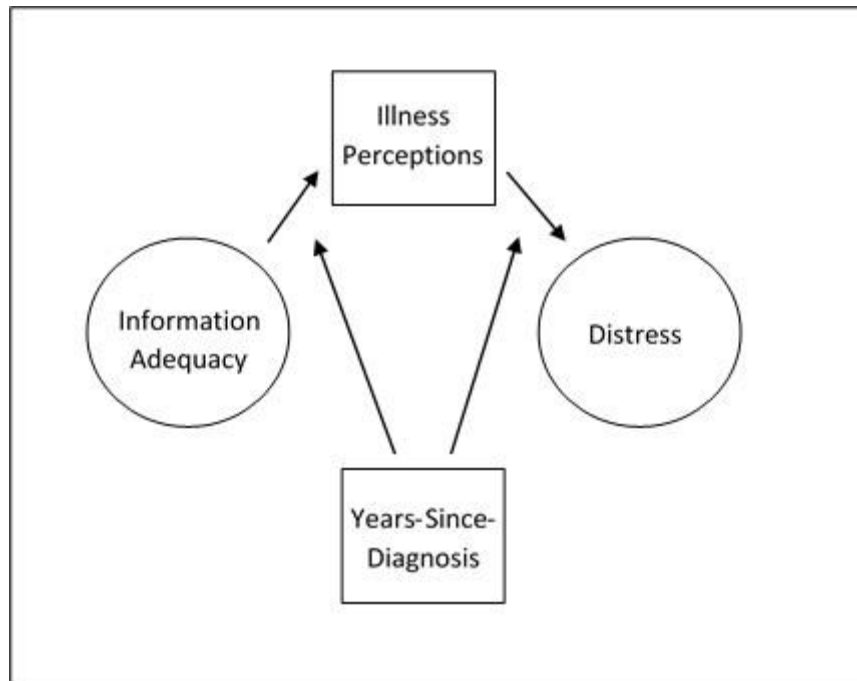


Figure 3 *Model 2.1: Conceptual model of hypothesized moderation effects of Years-Since-Diagnosis*

Model results did not support moderation hypotheses: neither interaction variable demonstrated a significant relationship at the hypothesized location in the model. Given these results, we decided to test each moderation hypothesis in separate models. Specifically, we evaluated whether years-since-diagnosis moderated the relationship between information adequacy and illness perceptions, and then evaluated whether years-since-diagnosis moderated the relationship between illness perceptions and distress. Results from these analyses corroborated initial moderation findings: neither interaction variable demonstrated a significant relationship at the hypothesized location in the model, evidencing a lack of support for moderation hypotheses. Further, the models did not support a direct relationship between years-since-diagnosis and distress, as this pathway did not reach significance in any of the tested models; however, a significant direct pathway from years-since-diagnosis to illness perceptions

was observed in several models. Therefore, an unplanned statistical analysis was conducted: a model was evaluated in which a direct pathway from years-since-diagnosis to illness perceptions was included as the only revision to Model 1.2. The resulting model (see Figure 4) suggested that the model fit the data well (RMSEA = 0.024; CFI = .995; $\chi^2(19) = 22.091, p > .05$). All direct and indirect pathways in the model were significant. Specifically, the direct pathways from information adequacy to illness perceptions ($\beta = -0.135, SE = 0.063, p = 0.033$), from years-since-diagnosis to illness perceptions ($\beta = -0.135, SE = 0.059, p = 0.022$), and from illness perceptions to distress ($\beta = 0.535, SE = 0.050, p < .001$) were all statistically significant. Additionally, the indirect pathways from information adequacy to distress via illness perceptions ($\beta = -0.072, SE = 0.035, p = 0.040$) and from years-since-diagnosis to distress via illness perceptions ($\beta = -0.072, SE = 0.033, p = 0.029$) were both statistically significant. Thus, the model demonstrated that greater information adequacy and more years since diagnosis were associated with better illness perceptions, and better illness perceptions were associated with less distress. Further, greater information adequacy and more years since diagnosis were both associated with less distress, via relationships with illness perceptions. This model accounted for 28.6 percent of the variability in the distress latent variable.

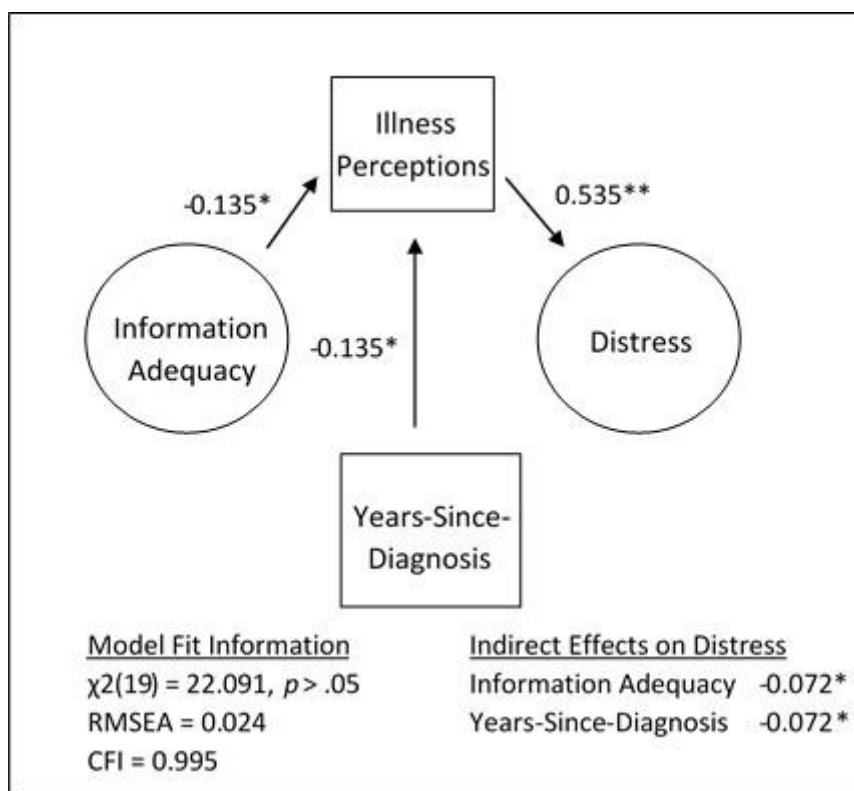


Figure 4 Model 2.2: Statistical model including direct relationship between Years-Since-Diagnosis and Illness Perceptions

* $p < .05$; ** $p < .01$

Discussion

Results revealed significant relationships between information adequacy, illness perceptions, and distress among survivors of DTC. Study hypotheses were largely supported: greater information adequacy was associated with better illness perceptions, better illness perceptions were associated with less distress, and greater information adequacy was indirectly associated with less distress, via associations with illness perceptions. This study is the first to establish these relationships among survivors of DTC. Such results are mainly consistent with existing literature regarding basic relationships among these variables in other cancer populations.

Contrary to studies with other cancer populations, a direct relationship between the information and distress variables was not established. All individuals included in the PROFILES registry were diagnosed with DTC more than two years prior to data collection. Given that previous research has largely demonstrated direct relationships between information experiences and distress in patients more recently diagnosed (see Husson et al., 2011b), future research should examine these relationships among newly diagnosed DTC patients. Such research may illuminate the extent to which absence of moderation effects in the current study can be attributed to patient characteristics (i.e., diagnosis more than two years prior to data collection). The present study also did not demonstrate a direct relationship between years-since-diagnosis and distress. Such results contribute to a mixed, but growing literature on the topic. Future research comparing distress among recently diagnosed patients versus among long-term survivors may illuminate the extent to which distress levels differ between the initial treatment period and long-term follow-up. Thus, results from the present study highlight the importance of further investigation regarding relationships between information adequacy, illness perceptions, and distress among recently diagnosed DTC patients.

The observed direct relationship between illness perceptions and distress in the present study highlights the importance of future research regarding methods to address patient illness perceptions. In the current study, both information adequacy and years-since-diagnosis demonstrated significant relationships with illness perceptions. While significant in the present study, the relationship between years-since-diagnosis and illness perceptions was not significant in another study of illness perceptions in DTC survivors (i.e., Hirsch et al. 2009). Given the lack of research on this topic, future studies may further examine and clarify this relationship. Further, future research is required regarding interventions (e.g., informational) that healthcare

providers may employ to address illness perceptions (Hirsch et al., 2009). The present study confirmed statistical viability of an information adequacy latent variable that may facilitate further examination of relationships between information adequacy and illness perceptions in DTC patients and other populations. Other aspects of patient information experience (e.g., overall satisfaction with information, perceived clarity of information, objective quantity of information provided) should be explored as avenues through which DTC patients' illness perceptions and distress can be addressed. Prospective studies with newly diagnosed patients should examine the effectiveness of such interventions over time. Further, given the response burden associated with other illness perception measures, the B-IPQ was a natural choice for inclusion in this large-scale survey collection; however, the IPQ-R factor structure may be ideal for future research on intervention effectiveness for particular cognitive and emotional illness perceptions domains. Further, use of the IPQ-R may facilitate exploration of relationships between illness perception domains and distress among DTC survivors. Thus, the present study demonstrates an important relationship between illness perceptions and distress among survivors of DTC, and highlights the need for future research regarding interventions to address illness perceptions in this population.

Overall, the present study extends knowledge regarding DTC-survivors' distress. Illness perceptions were directly implicated in patient distress, highlighting the importance of addressing patient illness perceptions throughout course of treatment. Further, study results were found for a population diagnosed, on average, 9.76 years prior to data collection. Thus, the present study suggests that healthcare providers should continue to evaluate and address illness perceptions in survivors of DTC throughout the course of long-term care; interventions to address illness perceptions in DTC survivors should not be limited to the initial diagnostic

period. Further, results of structural analyses revealed information adequacy as a method to directly affect illness perceptions, and indirectly affect distress levels. Future directions include development and research of interventions (e.g., informational interventions) to address DTC patient distress via impacting illness perceptions. In the present study, time did not affect the relationship between information adequacy and illness perceptions among long-term survivors. Such results suggest that patients may benefit from improved information experiences throughout the course of long-term care, emphasizing the importance of continued communication between medical professionals and patients. Study results also invite investigation of illness perceptions as a mediator of established relationships between information adequacy and distress in other cancer populations. Future studies should also investigate whether illness perceptions mediate relationships between other information experiences (e.g., overall satisfaction with information) and distress in patients with chronic illness. Such studies may illuminate the extent to which illness perceptions serve as mechanisms of action for relationships between information experiences and distress. Thus, this study contributes to a growing body of literature regarding distress in patients with a history of DTC, and provides a framework through which information experiences, illness perceptions, and distress may be investigated in patients with chronic illness.

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